

Caring for Individuals with Autism in Washington Task Force

Combined Public Input From Past ATF Meetings, Events, Emails, Comment Cards

OPEN PUBLIC FORUM, VANCOUVER, WA
MARCH 2, 2006 4:30 – 5:30 P.M.

Task Force members present: Dawn Sidell (Parent), Diana Stadden (Parent), Krista Johnson for Carol Taylor (Autism Outreach Project), Ron Yauchzee (School Districts), Monica Meyer (Educational Service Districts)

Audience attendance: 45 people

An overview of the purpose of the task force, its structure and its timelines was provided by task force members. Task force is looking at recommendations from other states.

Questions/concerns provided by audience:

Who gave dental input to task force? We need to hear both sides of the mercury issue. We need more education for dentists. Dental fillings are 50% mercury. We need to stop putting toxic material in children. When is the meeting about dental? Somehow you have to get the feds involved for funding.

We need training for pediatric doctors.

When primary insurance is not DSHS there is trouble with co-insurance. We need to train the insurance companies to accept the spectrum as real.

“Haves and have-nots” There is a huge gap between who gets what. We need to also have transition services for low functioning level children

There is no help from the state if you have a high IQ – NO HELP! It’s scary. What’s going to happen later? We need transition for higher functioning as well.

I graduated from Evergreen College, but I can’t stay focused. I’m smart, but I can’t figure out what to do or where I fit. I’m a man out of place.

Parents are denied services by schools. The schools are playing games with parents. Without an advocate nothing happens. We need a what-to-do booklet for parents, something simple: Here’s the Diagnosis, Now What?

My issues are medication and puberty. There is confusion about medications. What about co-morbid conditions? Where do you go to find a doctor who understands autism for your child?

Aspergers is always different, even though it doesn't look it. People are afraid of me. It's like a wolf pack. I'm seen as weak. People think those with Aspergers will "go postal" because of media reports. As someone with Aspergers I need help and understanding from my peers.

We need an autism endorsement for educators and medical professionals.

Military services – I'm frustrated with misinformation and the ridiculous hoops one has to go through. I had to prove sensory integration problems. Who qualifies the insurance companies to deny services? There are lots of brick walls with insurance companies. The family is punished because the parent stays home to help. My child was in therapy for 22 months and then services were denied. The WACs we have for insurance are not beneficial. They are destructive to employers who want to provide services.

I watched my wife struggle with losing her job because of lack of people skills. The Aspergers life is long, but there is no support in the job field or in the community. As a husband, I struggle with the effects of this all.

My husband has life insurance, my typical son is covered, but my autistic daughter is not because the insurance company won't cover her.

We need a list of dental providers who will work on those with autism. My adult son has major problems and has been bounced out of homes. The saddest day was when he graduated from high school. Government services are an incredible waste. Programs come and go. The nature of government is that they forget who they serve. Private organizations seem to get you the help you need. Schools do not recognize the need for sensory integration.

The most fun time I have had was when I had breast cancer. I got services and people listened to me.

Services for waivers: the rules are not interpreted correctly. We need standardization for qualifying services and waivers.

Where's the support for young adults? When you turn 21 there is no more educational support.

Education needs support groups and training for school districts. We need money in grants for staff development for Autism Spectrum Disorders. Health insurance for DD needs to be responsible for home therapies. We need BCBA certification and recognition of those who have it.

Employers and private businesses are willing to hire people with behavior difficulties, but they must have a tax incentive to hire people with autism.

PUBLIC INPUT FROM AUTISM TASK FORCE MINUTES

November 14, 2005 – No comments noted.

December 8, 2005 – No comments noted.

January 4, 2006:

1. TVW and public access
Need “ordinary” parent representation and increased diversity on the ATF; TC-TV offer for an interview.
2. Focus on ASD – not broader issues.
Address issue of those who have ASD but do not have developmental disabilities.
Funding for individuals with ASD who do not have DD is a problem; do not qualify for programs offered by DDD. They have no funding.
3. Elementary and secondary students/adults with ASD
Suspensions and containment
Many in correctional facilities may have ASD.
4. Concern expressed that adult issues need to be addressed more fully by the ATF.
Person felt that the limited seats on the task force are not representing DDD, DVR, and Adults and felt that the ATF seems to be focusing on 0-3 and 3-5.

For Action: Ensure and enhance continued participation Linda Rolfe/ DDD and others who represent life span issues.

OSPI can't tell a school district what to do. To work with school districts, you have to go from school district to school district.

Per Ilene Schwartz, **provide incentives** at the local school district level to increase involvement. Accept the NRC report as our base.

February 13, 2006:

A member of the public discussed reasons to ban the use of mercury especially in dental fillings and passed out literature.

March 13, 2006:

A member of the public informed the task force about a book on thimerosal in vaccines and discussed concerns about mercury in dental work.

A member of the public noted that capacity is at the core of this issue, remarking that many of the 'emerging issues' identified by the task force were about teachers and noted the need to partner with teachers and support them with adequate resources. Person requested that the task force cover more issues related to families dealing with stress and not knowing about options and reminded the task force that the divorce rate is high among families with a member with ASD. Recommended that the task force always keep 'do no harm' in mind when looking at best practices.

Written comments were collected from the public in attendance and are as follows.

Commenter #1

Thank you for noting that children do not cease being in the autism spectrum at age 18. Please continue to direct attention to ongoing services.

Commenter #2

There wasn't enough time to speak about the two "visions" or two kids where one was more cognitively affected and less affected socially, other was much more cognitively capable and much less socially affected. Who gets what services? State level mental health FYI transformation grant is allowing 2-3 hours with no limit on speakers in public testimony. Maybe you could publish the time limit for public comments?

Commenter #3

One autistic child had had 4 high copper mercury fillings placed in his mouth. This would be very negative to his health as his autism disease driver is mercury. One 14 year old autistic child had been given a thimerosal containing flu vaccine recently which made him very ill. Protect autistic children from mercury--chelate out the mercury they already have in their bodies.

Commenter #4

Need to look at other models of care that may be more intensive early on but less so over time like Early Bird Program in UK articles provided for review.

Commenter #5

Need to incorporate sexuality training for parents, young adults and teens with ASD so that families can openly discuss sexuality with their teen based on individual needs, based on function and engagement of the person involved.

Commenter #6

Need to proactively increase training programs for specialists like speech therapist, social workers, physical & occupational therapists at the University level and to encourage in these training programs to increase research in their field for best practices for children with autism in order to address the high rate of new diagnoses. Need for schools (teachers, counselors, and therapists) to place high priority on social and interactive skills particularly for higher functioning kids (elementary through high school age) in order to improve outcomes in work/over 21 year olds.

Commenter #7

The model of physician cooperating in the developmental team with the school that is practiced in DODDS/EDIS is likely the best way to have a complete assessment and treatment plan as opposed to keeping medical separate from the educational researchers.

April 24, 2006:

Five members of the public signed up to address the task force.

Member of the public is an 'unserved family.' Her child was not diagnosed by his pediatrician, a stranger in the grocery store suggested autism. Her son never got birth to three services or ABA services. She tried to get services through Medicaid but couldn't get the behavioral analyst services covered. (See Minutes from April 24 for fuller comment).

Medicaid reimbursement rates are too low for providers to make an effort to complete the petition forms. She noted that some studies suggest that children get inflammation of the brain from elements in their diet (gluten, casein, and soy). These theories are not recognized by doctors and social service providers – e.g. special diets are not covered. She passed around pictures of his handwriting. Since dealing with his medical problems through diet restrictions some things have improved. She commented that she doesn't understand why the medical basis for children's behavioral problems are not addressed – most approaches emphasize education and behavioral modification.

A member of the public provided handouts to the task force and offered recommendations to the task force and asked them to help the group advocate to the Legislature about mercury. She read from the resolution that she distributed.

A member of the public is a public health nurse and also a student. She recently worked with the Clark County Health Department managing the back to work program for TANF families. She found that several of her colleagues noted that families on their case loads have children with autism but cannot find child care for them. This prevents the families from returning to work.

A member of the public has a 3 and half year old child with autism. She spoke about pressure on parents to be advocates. There is a disconnect between the number of hours that the Autism Center recommends and the number of hours that they actually get. Medical disorders accompany autism so frequently that it is important to discuss them. Once they started to correctly address their son's medical needs his condition improved. She shared articles with the task force via email earlier in the week. She raised concerns about Merck's new vaccine 'ProQuad' and its health effects in clinical trials. Families need acknowledgement of medical disorders that accompany autism.

A member of the public who is a parent of a person with ASD said family didn't realize until individual was an adult that she was on the autism spectrum. She wants to

emphasize that adults need services also. Caring for a person with autism is very expensive. The difficulties, in some regards get worse as people get older.

Comment Card—April 24, 2006

As I listen to the panelists there is considerable strength in the individuals. Any system should build on those strengths. In most their strengths were not used or supported. They all have needs in multiple parts of their lives. Families should have choices of which needs are met, should pick providers and prioritize their needs. Flexibility within systems seems to be important to allow families to make it happen. The more complex a situation the more flexibility is needed. Multiple funding streams with multiple case managers [is] detrimental to effective care. I am an advocate of a single plan of care and a single funding stream that can be used to meet identified needs that are by the family. A blended funding can be more effective, simpler, and increase satisfaction.

PARENT/ADULTS PANEL QUESTIONS AND ANSWERS FROM APRIL 24, 2006 ATF MEETING:

Morning Panel: Parents of Children with Autism Spectrum Disorder

Panelists: Angela Dawson, Julee Johnson, Ginger Kwan, Rhonda Meyers, Julie Perales

1. Please state your name and where you live. What is your child's diagnosis and current age? Your child's age at diagnosis? Do you have other children in the family? If so, how has Autism Spectrum Disorder impacted your other children?

Five parents of children with autism shared their experiences with the task force. The children ranged in age from 4 to 25 years old. Three of the children were diagnosed with autism around the age of 2 years; one child was not diagnosed until age six. Several of the children had multiple medical conditions in addition to autism. Three of the children have siblings. The parents reported that the autism diagnosis has made their other children very protective and more compassionate.

2. What has been your family's experience with medical/health professionals and health insurance prior to and since your child's diagnosis?

Three of the five panelists reported significant challenges with obtaining health care and insurance coverage for their children's needs. Problems included refusal of payment for services, lack of providers in insurance network, lack of hospital capacity to admit a child during a crisis situation, lost and ignored appeals for insurance payment, and refusal of care because insurance would not pay bills. Two families have not had significant problems with insurance companies but reported some problems with finding health care providers who were knowledgeable about autism. A few parents indicated that their children receive some services through their school districts. Experiences with the Autism Centers were positive. Problems with insurance and health care create stress and parents often feel helpless and desperate.

3. What school and community based supports and resources have been available to you and your family? Which have you found to be most helpful? What are the problems or gaps you have run into?

Parents noted that the Internet was a good resource for those that have access to it, but not everyone does. Also support groups and other parents (e.g. Parent to Parent and Father's Network) are very helpful. The parents felt that inclusive school programs were very helpful and important; regular education students have been very accepting in some cases. One parent mentioned the former MESH program in the Lake Washington School District as a model program. The Birth to Three Early Intervention Program was noted as being very beneficial. Other helpful resources include Parks and Recreation programs, Scout summer camps, one on one school aides, well trained teachers, family and friends, conferences, therapists, school districts, and the government. One parent has not had a good experience with her school district and several parents expressed frustration with the Division of Developmental Disabilities (DDD). Parents noted that some gaps result from language and cultural barriers, waiting lists, financial burdens, lack of skilled providers, need to travel long distances for certain services, and geographical/regional differences in services.

4. Were you supported when your child was transitioning? Please describe how and how not. You can refer to the transition that is most recent or most important to you, whether from 0-3, preschool, kindergarten, elementary, middle school, high school, or adulthood.

In general, parents felt that the Birth to Three program was very helpful with transitions to preschool. Transitions to primary, middle, and high school were generally more challenging and involved a lot of self advocacy and efforts by the parents. Many felt like there were enough consistencies between systems and that little guidance is available to parents regarding services and their rights. For the one child who has finished high school, a community transition program and connections with employment agencies and DVR were very helpful. One parent had a very good experience with the Highline School District and her son's transition to primary school. Parents expressed concern about the effect of budget cuts on programs. It was noted that it is difficult to find after school care for older children.

Discussion regarding the morning panel:

The task force asked the panelists several additional questions.

Question from the Task Force: what is the impact on siblings?

Parent: my kids don't treat my child with autism any differently, however when his brothers and sisters hear other kids teasing them, they talk to the kids about why that happens; my kids learned to be more compassionate and caring through this support of their brother.

Parent: my daughter is only 17 months older than her brother with autism; she is very protective of him. We have several cousins close in age and they all make sure he is taken care of. Now that my daughter is older they are actually beginning to fight with

each other and she is not only supportive of his needs; she is very compassionate because of these experiences.

Question from the Task Force: one of the thematic issues across all the families was the importance of the birth-3 programs; our recommendations should absolutely highlight this infrastructure to help with the early diagnosis. We heard in our first meeting that the delay in the diagnosis among children of diverse ethnic backgrounds is much higher than the rest of the population; the parents have mentioned the importance of the ethnic outreach to families; they are the ones, like Julie, who are unaware of what the system offers them and take it upon themselves to seek out what is available, not the system informing them. A question I have for the parents, the mental health needs of the children as they age, and for the parents is critical. Statistics tell us that these parents are the ones who will get into addictions because of the assistance they need along the way. Kids with autism have a tremendous amount of stress and sometimes our systems don't include that in support to them as they age, and support to the parents. As the kids get older, there is more pressure on them—suicide is also an issue. Parents, what are your experiences as it relates to mental health?

Parent: one of the great things about our son is that he has a very positive self-esteem and as far as we know is pretty much unaware that he isn't just like all of his peers, which from a mother's perspective is a good thing; however, he does have some anxieties and in recent years we have given him medication for that—we think it is helping; we have discussed what else we should be doing; we don't think talk therapy is something he would respond to; we have tried to problem-solve with him in a neutral setting to say if this happens, then we/you will have to do this—to problem-solve; mental health issues for the parents, both my husband and I have had to tackle that head on—we know the statistics of problems with marriages and relationships; I have had the luxury of being able to have a therapist whom I trust and I can go to and I have used that; another thing that is helpful is our Mother's group—we call ourselves Mother's from Hell—we band together and talk about what life is really like at my home and I don't do that in a lot of settings.

Parent: my son is still being served by the mental health system in King Co. and the Medicaid waiver program referred him to a behavioral psychologist who has been seeing him for years. Unfortunately the system does not always support children with autism for behavioral issues; my son is non-verbal and relies on a communication device to communicate, but he often refuses to use the device. We rely upon a behavior plan to help him express himself; whenever the environment changes, or some of the big transitions come up he has those anxieties (e.g. WASL). My son acts out when he cannot communicate what is going on in his environment. We try to keep him happy so he can deal with the anxiety issues better. We have a great support from our church community and they have been supportive of him and accept him as part of the community; they also provide 1-1 support to him in Sunday School; as parents we can then go to our own classes for spiritual growth. Families who speak different languages, that is often a stigma when you talk about mental health—there is a cultural stigma against it—a negative perspective about mental health issues—we need to change this cultural stigma to inform families.

Comment from Task Force: the Legislature did pass a bill this year to get the birth to three program in every school district; regarding WASL, kids with autism challenges are being required to take the WASL and it has really upset them because of the change in their routines; those are issues that we do have to address; we need to address the need for 1-1 support for all kids with autism at school is critical.

Parent: I welcome any help, I have brought in medical professionals to the school and the district refuses and I watch other parents that just can't believe that I can't get a 1-1 aide for my child in the Highline School District.

Comment from the Task Force: we're glad the birth to three program now is mandated and we're hoping OSPI will provide funding; the training of the providers, whether it's school staff or kids in the classroom, it begins with the teacher and the aides in the classroom—my daughter said they need to mandate that the teachers and the aide's need training about what autism is all about.

Parent: my mom is willing to help, but she has raised her kids and she doesn't need to raise my son—that's how I was raised with a challenge in asking for help.

Comment from the Task Force: we're all stressing the training and the cultural context that needs to be included in the training; there is also a need for standardization regardless of where they are we need to assure all kids gets the same quality of intervention. A parent and the family shouldn't have to be isolated because of exhaustion because our services have no standardization. This is a fundamental issue in our state and we need a recommendation that will steer us in that direction—with good evidence—so we can get that.

Comment from the Task Force: another thing I heard is the importance of home visiting and wrap-around services; the best trained school teacher is not going to be able to support parents if they don't know what is going on at home; no one has mentioned summer and children and parents need wrap-around services that are funded; the continuity between home and school needs to be improved.

Parent: many of us as parents have funded and run our own programs (e.g. three sites in King County), but we need support.

Question from the Task Force: you (parents of children with ASD) are what this Task Force is all about; it sounds like you're forced to leave your own communities and travel to other places to find the support you need; it sounds very isolating when you don't have the support you need in your own community; what we really need is training that goes statewide so families have the expertise at home and in their own districts—what is your sense of that?

Parent: on top of that, we need to make sure we have staff that are well trained so families with limited English proficiencies won't be left out as they are now.

Parent: a lot of the services say "we serve autistic children" but that is not always true in different communities; parents of lower functioning kids are more isolated, literally our life is home-school-doctor and that is our community.

Parent: regarding statewide training, within King County there are many different forums, but you see the same people going to those all the time—the ones who know about those things; but people who may have cultural blocks and blocks in finding out about them is of concern.

Question from Task Force Member; there is some training out there to understand what your rights are in the school district. Is that known to people in your school district?

Parent: based on my experience I am an advocate person but I lead with my heart and my emotions and when I get too much information I get spooked and I don't know which direction to go. Especially in my ethnic background there are many fathers who think they need to be the strong one and not to ask for help. Being in denial is your worst downfall. Thank goodness for the Father's Network which has helped my husband. We help other family members who are in denial about the fact that their child needs help. Support for families (e.g. therapists) is needed. Sometimes it's better to go to a professional instead of a family member.

Parent: I access training all the time because I'm working in this field; other families are not able to access training because of cultural (or knowledge) barriers; some parents don't even know what an IEP (individualized education plan) means.

Question from Task Force Member: needing to coordinate many different providers, what happens when families do not have the resources to do that coordination? In Oregon there is case management for children with disabilities.

Parent: we need well-coordinated services for our kids, we need someone who can be the coordinator to communicate with different providers, then families no longer need to tell the story over and over again; well coordinated services are so important but our current system is not funded in that area.

Parent: that coordination needs to be effective, DDD sends home health care nurses but that is not meeting the need; basically they come once a year and you hand them a list of all of the child's needs and medications; it's just one more person who wants to gather the information and doesn't want to offer any help to families.

Afternoon Panel: Adults with Autism Spectrum Disorder
 Steve Johnson and Eric Johnson, Kenny Miller, Deborah Thorsos, Philip Carpenter,
 Amanda East

1. Background

- a. Please state your name and where you live.
- b. What is your diagnosis and what was your age at diagnosis?
- c. What has been your experience with medical/health professionals prior to and since your diagnosis?
- d. What has been your experience with the school system?

Five individuals with autism spectrum disorder (ASD) addressed the task force. The panelists were diagnosed with ASD at different ages: six years, 24 years, 2 years, 10 years, and 41 years. Some of the panelists reported experiencing many wrong diagnoses and being prescribed inappropriate medications. Most of panelists reported that being diagnosed with ASD was a surprise to them and their families. Overall the panelists experiences with the school system were challenging. It was difficult to find an education suited to their style of learning. The higher functioning individuals were very successful academically in school but felt that their academic success did not prepare them for employment. One individual remembers going to speech therapists and a private school for children with special needs, both of these were helpful to her. However the association with a 'special school' affected her self esteem for many years. Some of the panelists went to school before much was known about autism and their experiences with teachers and students was not positive.

2. What supports have been helpful to you? For instance, please describe supports such as:

- Division of Developmental Disabilities (DDD)
- Division of Vocational Rehabilitation (DVR)
- Employment agencies
- Autism organizations
- Other agencies
- Other community supports

The panelists expressed frustration with many government programs such as Division of Vocational Rehabilitation (DVR) and Division of Developmental Disabilities (DDD). In general, the panelists felt that the agencies emphasize too many negative aspects of their disorder and don't accentuate the positive things. They also did not/do not receive adequate advice and direction with respect to education choices and employment referrals. The panelists don't think that DVR employees have an adequate understanding of autism or are trained properly to manage cases of people with ASD. People with ASD need continued career development support to help with career changes and handle transitions such as promotions or changes in job demands. Specific employment agencies and job coaches have been helpful for some of the panelists. Most of the panelists reported difficulties with getting appropriate employment.

3. Employment

- a. Are you employed?
- b. If so, what has helped you get a job and keep a job?
- c. Do you know about the new “working age adult” policy?
- d. What kinds of supports, if any, have you received to comply with this new policy?

One panelist reported that she is self-employed, two other panelists have jobs, two panelists are currently unemployed. DVR does not support activities for people to be self employed. All the panelists expressed a desire to work, earn and income to support themselves, and contribute to something.

4. Explain your living situation (live with family, on own, in residential).

- a. Are you happy where you live?
- b. Have you had problems finding or keeping a place to live?
- c. Would you want to change where you live, and why?

One panelist owns his own condominium, another lives in an apartment with a roommate. One panelist is married and lives in her own home. One panelist recently moved out of his family’s home and is living in a shelter, seeking permanent housing. One panelist lives with her parents. Finding housing, especially shared housing/independent living has been very challenging. It is difficult to find people for shared housing and hard to afford to live on their own.

The task force members asked the panelist more questions.

Task Force Member: Has someone bullied you?

Panelists: Kids make fun and people move to another seat on the bus or cross to the other side of the street. Growing up, kids teased, bullying is different among adults. Adults will exclude people from their activities or make excuses to not include you.

Task Force Member: Asked Kenny to share some law enforcement experiences.

Kenny: His local police know who he is, but when he is visiting his mom in Seattle, the police don’t know him and sometimes he is confronted. He carries a card that says who he is and explains he has autism. When he shows them his card, they are usually very nice.

Task Force Member: Asked about friendships and social networks.

Panelists: A couple of panelists commented that their communities are generally welcoming and supportive, especially familiar people and friends. Another panelist noted that she has been a social hermit, most of her social life happens over the computer.

Task Force Member: Commented that the bullying described by the panelists sounded like discrimination.

Task Force Member: There is a need to prepare employers/human resources for the up and coming number of potential employees with autism. There is also a need to train people for employment, educate them with a plan in mind that is based on their strengths. Individuals with ASD need to be prepared beyond childhood.

Task Force Member: Asked what Eric's employment is and how much he gets paid.

Eric: His current job is at Brambleberry. He works in an assembly line filling bottles with fragrances. He was originally paid competitively, currently he is paid less than minimum wage in order to be retained because his production is not the same as the non developmentally disabled employees.

Task Force Member: What is the role that parents are taking? Do parents provide resources for children to live independently? What should parents plan for?

Steve Johnson, Eric's father replied that estate planning and special needs planning are very important. Some parents are able to put together some resources to buy residences for their children. Some individuals qualify for Section 8 housing allowance and can have their own apartment.

EMAIL INPUT:

A parent provided a number of articles which have been forwarded to literature subcommittee lead (Ilene).

A doctor said I have long been frustrated with the state's failure to assign clear responsibility within DSHS for services to children and families with autistic spectrum disorder. The DMH Access to Care Guidelines specifically excluded the Autism, Aspergers and PPD NOS diagnoses from the included diagnoses list. I complained about this all along the way noting that Autistic Spectrum Disorders (ASD) were always included as diagnoses for which the field of child and adolescent psychiatry had special skills and knowledge. Most of the research and the many (frustratingly ineffective) treatment efforts came from C&A psychiatrists. My fear is that given the composition of the panel our state's unusual presumption of ASD's being primarily the province of DDD will likely continue. In difficult cases that emerge in our emergency rooms with these sad children and young adults, we are unable to provide any services unless there is a secondary allowed diagnosis.

I know that the work of the panel is nearing completion but I was wondering if there was any room for inclusion of child and adolescent psychiatry before it finishes its work? I see some psychologists from the UW, but I don't think they are affiliated with the Div of C&A Psychiatry. Has Bryan King, the new chair of this division been tapped at all? He is a national expert in ASD's. It would seem that he or someone from his inner group should have been involved in this committee and if he hasn't been to date, perhaps it wouldn't be too late.

Victoria Crescenzi, MD, CDR MC USN, Developmental And Behavioral Pediatrician
Based At Naval Hospital In Bremerton

Thank you for keeping me listed with this e-mail, I would like to make a comment about "What needs to be rewritten"

1. When discussing children with Autism Spectrum disorders treatment must include trained mental health professionals who understand autism in school and in community setting, and they must be eligible for payment to these mental health professionals, ie LCSW, Psychologists. Often times more highly functioning children with ASD need treatment with social skills, or anxiety among a number of other problems that can be treated but the diagnosis of Autism denies them access to these providers. Social skills can best be treated in the school setting where the peers are to engage in social skills training, but the counselors there often do not understand all the nuances of treating children with ASD. In Private practice psychologists often have the expertise to at least teach some of these skills but there is no ability to pay for these services. This quandary leaves the family without any resources for support, particularly when the child is higher functioning and there could be great gains with the right support.

Another problem that occurs is many health care benefits providers and insurance companies provide service to those children with the most severe disability, although often not nearly enough, but deny service to those children with ASD who do not also have mental retardation. For instance This is only one example of many. The TRICARE ECHO program will cover ABA services, (if available by a certified therapist which are few and far between) but the child needs to have demonstrated severe impairments such that he is homebound, unable to perform any ADL's etc. this excludes children with autism who do not also meet definition for mental retardation, although what scientific evidence there is for ABA and other therapies suggests that they may benefit more the higher functioning children who are higher functioning.

This essentially denies service (if available) to those who could use it most.

Similarly, in TRICARE for children 0-3/ and 3-21 who have delays notably between 1.5 SD and 2 SD below the mean they are denied service because they are not severe enough, and for those children greater than 2 SD below the mean they often only allow for minimal service, 1 x per week although the literature has long showed that more intense, more frequent and more direct treatment has been most beneficial for children with ASD, no matter what particular service style one would happen to use.

These broad denials of care for children based on short sighted antiquated ideas are not helpful to the families; it wastes precious time for the children to get intervention. Literature and practice has shown that early frequent intense intervention really impacts and improves on outcome in the long run, and the children remain in service longer causing greater costs to the very people who are trying to save money by denying them in the first place.

Please keep these comments for the May 22 meeting.

INVENTORY/SURVEY COMMENTS**Jai Jeffries and Dr. Gary Tart**

Question 1. Please list any reports, journal articles, or other research literature you consider “required reading” for the ATF. Knowing that there is an extensive amount of scientific literature available; provide your top 5 articles or references.

Jai Jeffries

I’m sure members are familiar with these references. “The Autism Fight”, however, may be new to most. It offers a snapshot of the parenting experience and a framework for what’s broken.

Title: *Educating Children With Autism*

Publisher: *National Academies Press; 1st edition (October 2001)*

ISBN: *0309072697*

Title: *Let Me Hear Your Voice*

Publisher: *Ballantine Books; Reprint edition (July 19, 1994)*

ISBN: *0449906647*

Title: *The Autism Fight*

Publisher: *Susan Sheehan in The New Yorker, December, 2003*

Title: *A Work in Progress: Behavior Management Strategies & A Curriculum for Intensive Behavioral Treatment of Autism*

Publisher: *D R L Book, LLC (May 1999)*

ISBN: *0966526600*

Dr. Gary Tart

Having lived in both New York State and Washington, I can say that we were much more satisfied with the schools and the services provided in school for our son in New York. I don’t think this has so much to do with a best practice model as it does with funding. Public schools and special education are better funded in New York. Schools had more support staff such as speech pathologists, psychologists, classroom aids and school nurses. Children with autism need the help of classroom aids, especially those who are mainstreamed. They also need speech and language services to help with pragmatic language skills. They need assessment by psychologists skilled in evaluating children with autism. The whole team must focus on helping the child achieve success socially. We found it much easier to get such services for our son, and as a pediatrician I found it much easier to get services for my patients in New York. The attitude of the school team in New York seemed to be one of always looking for additional ways to support a child as opposed to one of providing the least amount of required support. The ATF should advocate for Washington State to adequately fund special education.

Question 2a. Describe features of these models in other states that you consider especially valuable. See list below, and provide comments where appropriate:

Funding

Early screening and diagnosis

Treatment and therapies
 Family support
 Individual support (transition and adult treatment)
 Other

Jai Jeffries

Funding

"Katie Beckett" waiver (CAP waiver) works elsewhere

Other

Some states define, by law, that autism as a neurological disorder.

17 states (including CA, TX, IN, NJ, CT) mandate insurance coverage for therapies.

Dr. Gary Tart

Having lived in both New York State and Washington, I can say that we were much more satisfied with the schools and the services provided in school for our son in New York. I don't think this has so much to do with a best practice model as it does with funding. Public schools and special education are better funded in New York. Schools had more support staff such as speech pathologists, psychologists, classroom aids and school nurses. Children with autism need the help of classroom aids, especially those who are mainstreamed. They also need speech and language services to help with pragmatic language skills. They need assessment by psychologists skilled in evaluating children with autism. The whole team must focus on helping the child achieve success socially. We found it much easier to get such services for our son, and as a pediatrician I found it much easier to get services for my patients in New York. The attitude of the school team in New York seemed to be one of always looking for additional ways to support a child as opposed to one of providing the least amount of required support. The ATF should advocate for Washington State to adequately fund special education.

Early Screening and Diagnosis in Washington

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

Dr. Gary Tart

Screening is an area in which there is much room for improvement. It is possible to identify many children as early as eighteen months of age, and the responsibility for this lies mostly with medical providers who see children. Pediatricians and other medical providers need more information on the use of screening tools. The articles I listed provide some of the most recent published guidelines. Children who are identified as possibly having autism, should be referred ideally to a center that provides a multidisciplinary evaluations or to a specialist such as a child psychologist, developmental pediatrician or child neurologist experienced in making this diagnosis. The local resources I am most familiar with are the Autism Center at the University of Washington, the child development clinic at Mary Bridge Children's Hospital and Pediatric Psychology at Mary Bridge. Children can also be referred directly to Birth to Three programs to begin early intervention services and this can be facilitated through family resource coordinators. I am not very knowledgeable on funding but assume it comes from a combination of federal and state dollars as well as direct billing for

services. This most obvious shortcoming is the wait time for evaluations at the larger centers and sometimes the wait to begin services.

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

3c. What are best practices in your opinion related to early screening and diagnosis?

Jai Jeffries

Reference: Autism A.L.A.R.M, derived from policy statements of the American Academy of Pediatrics and American Academy of Neurology.

Reference: CDC campaign “Learn the Signs. Act Early.”

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

Dr. Gary Tart

A variety of treatment services are available. For most of my patients, the school district becomes the main service provider. Children may receive special education services from teachers, speech services, PT and OT services in the school setting. Some school districts have birth to three programs and others begin services at three. Many children receive additional services outside of school through private providers such as physicians providing medication management, speech pathologists providing more intensive therapy or psychologists providing group or individual therapy. Young children may receive behavior services from providers certified in techniques such as applied behavior analysis. Such privately obtained services are often difficult to find or are difficult for families to afford, as they may be expensive, may not be well covered by insurance and many providers do not participate with Medicaid or Healthy Options Plan.

The development of best practices in treatment is a difficult task at this point because national experts cannot agree. Families are presented with many types of possible treatments, some of which are supported by excellent studies and some of which are based only on anecdotal reports. Deciding which types of treatments to pursue can be frustrating. There simply isn't adequate information available on certain types of treatments at this point. The ATF should seek information from national groups such as the Autism Treatment Network and The National Alliance for Autism Research if they will be making recommendations on the types of treatments that should be funded. They should also consult specialists from research centers, such as the Autism Center at the University of Washington.

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4b. Who funds these treatment services?

Jai Jeffries

Few families can afford science-based treatments to address this disorder properly.

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4c. What are best practices in your opinion related to treatment services?

Jai Jeffries

In my opinion, it would be the common elements of effective programs as detailed by Dawson and Osterling in "Early Intervention in Autism" and the NRC recommendations in "Educating Children With Autism."

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4d. What are the shortcomings?

Jai Jeffries

Community-based treatment programs generally fit the parameters of research groups that realize no gains, statistically. Examples might include:

*Jane S. Howard, Coleen R. Sparkman, Howard G. Cohen, Gina Green and Harold Stanislaw **A comparison of intensive behavior analytic and eclectic treatments for young children with autism** Research in Developmental Disabilities, Volume 26, Issue 4, July-August 2005, Pages 359-383*

*Sigmund Eldevik, Svein Eikeseth, Erik Jahr, Tristram Smith, **Effects of Low-Intensity Behavioral Treatment for Children with Autism and Mental Retardation**, Journal of Autism and Developmental Disorders, Mar 2006, Pages 1 – 14*

*Eikeseth et al. **Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study.** Behav Modif. 2002; 26: 49-68*

Lovaas, 1987; McEachin, Smith, & Lovaas, 1993

*Smith, T., Groen, A., Wynn, J., **Randomized Trial Intensive Early Intervention for Children with Pervasive Developmental Disorder.** American Journal on Mental Retardation, Vol. 105, No. 4, 2000, pp. 269-285.*

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4e. What issues and concerns do you want the ATF to address regarding services available for treatment?

Jai Jeffries

Health insurance coverage for intervention.

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

Dr. Gary Tart

Family support services are provided in a variety of ways. Emotional support and information may be provided by support groups in schools or in the community. The Autism Society of Washington and its local chapters provide these services in most parts of the state. Advocacy groups such as Washington PAVE help families deal with school districts. Those who qualify may be eligible for services such as respite care or housing assistance, but my understanding is that there are long wait lists. As with other areas, funding is the biggest issue. The ATF should advocate for adequate funding for agencies such as Medicaid and DDD, particularly since the number of affected children is increasing. The need for adult services is going to go up markedly over the next several years.

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5a. Who provides these services and for what age groups?

Jai Jeffries

The Life Opportunities Trust is an excellent program. As you know, ASD families must finance costly treatment programs while simultaneously saving for their child's future (note that saving for personal retirement is simply not an option for most of these families).

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5f. What issues and concerns do you want the ATF to address regarding services available to assist individuals with autism spectrum disorder?

Jai Jeffries

I believe this is a very important question and yield to members having experience with adolescents and adults.

Recommendations on future ATF expert panelists

Question 7. Please provide recommendations on individuals who you think will bring essential information to the ATF in the areas of best practices in diagnosis, screening, treatment, health care, education, employment, and support of individuals with autism spectrum disorder and their families.

Jai Jeffries

C. Gray and G.L. Burns at Washington State University are currently gathering information aimed at answering many of the questions contained in this inventory.

Representatives from one or more major insurance carriers should be on the panel to explain business barriers to intervention coverage.

LETTERS OF PUBLIC INPUT

May 8, 2006

Caring for Washington Individuals with Autism Task Force
Office of Maternal and Child Health
Department of Health
Community Health
111 Israel Road SE
Tumwater, WA 98501

Dear Task Force Members,

In follow up to our March 13, 2006 testimony to the Task Force as members of the physician panel, we urge the committee to make a strong statement supporting high quality intensive early intervention as the cornerstone of its written findings.

It should be evident to the Task Force that early intervention services in Washington are currently highly inconsistent and usually not of the best quality. Washington does not have a clear "standard of care". We contend that there is sufficient evidence for the Task Force to take an unequivocal position that provides impetus for important stake

holders, including health care providers, ITEIP, DSHS, and the public schools, to work together to offer and to fund more consistent high quality services for young children with autism. Decades of research show this to be the best method for maximizing the capabilities of persons with autism. In 1999, Mental Health: A Report of the Surgeon General stated "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate behavior." The literature in the intervening years only strengthens this conclusion. The Task Force should align Washington with this national position.

We have attached several articles from the literature supporting early intensive behavioral intervention. The most recent is from the Wisconsin Early Autism Program. It again demonstrates that with appropriate intensive early intervention, a substantial subset of children with autism do very well, with marked gains in cognitive and social function. This finding is distinctly different from the natural history of autism. It replicates the controversial Lovaas findings of the 1980s. Washington should replicate highly successful programs, not provide vague guidelines that encourage continuing to reinvent the wheel for every child. The Task Force has several members with significant expertise in similar approaches who can craft a well worded recommendation which would provide guidance to our various service providers. Key components would clearly include early initiation, structured curriculum and teaching environments tailored to unique individual strengths and weaknesses, sufficient intensity, behavioral oversight, family involvement, and early and consistent efforts to generalize developing skills to natural settings. Very few children in Washington are currently participating in programs that meet these criteria which offer the best chance of success. Behavioral oversight and intensity approaching the levels in the most successful studies are particularly infrequent.

A strong Task Force statement would be a first step. DSHS should recognize the validity of supporting evidence for intensive early intervention, and provide funding on that basis. Coverage of the services of certified behavior analysts, as Tricare currently does, is particularly important. OSPI must provide stronger leadership for our diverse school districts. ITEIP needs to consistently offer high quality services before age three and coordinate smooth transition to similar services in early childhood special education. Our Universities, particularly the University of Washington Autism Center, the new Autism Center-Tacoma, and the partnership of Eastern Washington University and Northwest Autism Center in Spokane, will need to provide expertise, capacity building, and direct services.

Washington has the potential to move forward dramatically in its early intervention services for autism. We hope that the Task Force will provide the needed strong leadership. We would be happy to provide further input if that would be of assistance. Thank you for all your efforts.

Sincerely,

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